

Senate Concurrent Resolution No. 75

RESOLUTION CHAPTER 64

Senate Concurrent Resolution No. 75—Relative to Friedreich's Ataxia Awareness Day.

[Filed with Secretary of State May 18, 2000.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 75, Lewis. Friedreich's Ataxia Awareness Day.

This measure would proclaim May 20, 2000, as Friedreich's Ataxia Awareness Day.

WHEREAS, Friedreich's ataxia is an inherited, progressive neurological disorder, usually diagnosed in childhood, that causes muscle weakness and loss of coordination in the arms and legs; impairment of vision, hearing, and speech; scoliosis; diabetes; and a serious heart condition. Most patients need a wheelchair full-time by their twenties and, in later stages of the disease, many become completely incapacitated. Life expectancy is reduced to early adulthood. There is currently no effective treatment or cure for Friedreich's ataxia; and

WHEREAS, Although there is no treatment or cure available to Friedreich's ataxia patients and families, they have more and more reason for real hope. An extraordinary explosion of research findings has followed the identification of the Friedreich's ataxia gene in 1996. Since that discovery, research scientists have learned a great deal about the disorder. They have identified and analyzed the protein that is deficient in these patients, and determined that the deficiency results in faulty iron metabolism, reduced mitochondrial function, and cell-killing oxidative stress. Scientists have also developed model Friedreich's ataxia systems in lower organisms and are testing these systems in human cell cultures and patients. Therapeutic clinical trials of promising drug compounds are now underway, with encouraging preliminary results; and

WHEREAS, Investigators are increasingly optimistic that they are drawing closer to understanding more fully the causes of Friedreich's ataxia and to developing effective treatments. Of course, the impact of a breakthrough in this disorder will not be limited to Friedreich's ataxia. As the Director of the National Institutes of Health (NIH) recently reported to the Congress, "As with progress in many rare diseases, what we discover about cellular changes and therapeutic approaches in Friedreich's ataxia may lead us to important insights about more common disorders"; and

WHEREAS, Within the NIH, the National Institute of Neurological Disorders and Stroke (NINDS) has primary responsibility for sponsoring research on Friedreich's ataxia and the other neurological disorders. The NINDS conducts research on Friedreich's ataxia and other forms of inherited ataxias at its facilities at the NIH and supports additional studies at medical centers throughout the United States and elsewhere; and

WHEREAS, Augmenting these government-sponsored efforts are programs supported by patient advocacy foundations and industry. The intensifying cooperation among these various sources of support for this research and the multidisciplinary efforts of thousands of scientists and health care professionals, provides powerful evidence of the growing hope and determination to conquer Friedreich's ataxia; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature hereby proclaims May 20, 2000, as Friedreich's Ataxia Awareness Day; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.

